

Supplementary Table 1. All eligible patient reported outcome questions assessed within the IBD Partners population for potential inclusion in the new Patient Reported Outcome Based Evaluation of quality of life in patients with IBD

In the past 7 days...	Original PROMIS Domain
I felt fearful Never, Rarely, Sometimes, Often, Always	Anxiety
I found it hard to focus on anything other than my anxiety Never, Rarely, Sometimes, Often, Always	Anxiety
My worries overwhelmed me Never, Rarely, Sometimes, Often, Always	Anxiety
I felt uneasy Never, Rarely, Sometimes, Often, Always	Anxiety
I felt worthless Never, Rarely, Sometimes, Often, Always	Depression
I felt helpless Never, Rarely, Sometimes, Often, Always	Depression
I felt depressed Never, Rarely, Sometimes, Often, Always	Depression
I felt hopeless Never, Rarely, Sometimes, Often, Always	Depression
I feel fatigued Not at all, A little bit, Somewhat, Quite a bit, Very much	Fatigue
I have trouble starting things because I am tired Not at all, A little bit, Somewhat, Quite a bit, Very much	Fatigue
How run-down did you feel on average Not at all, A little bit, Somewhat, Quite a bit, Very much	Fatigue
How fatigued were you on average Not at all, A little bit, Somewhat, Quite a bit, Very much	Fatigue
I am satisfied with my ability to meet the needs of my friends Not at all, A little bit, Somewhat, Quite a bit, Very much	Satisfaction with social role
I am satisfied with my ability to do things for fun with others Not at all, A little bit, Somewhat, Quite a bit, Very much	Satisfaction with social role
I am satisfied with my ability to do things for my family Not at all, A little bit, Somewhat, Quite a bit, Very much	Satisfaction with social role
I am satisfied with my ability to do work really important to me Not at all, A little bit, Somewhat, Quite a bit, Very much	Satisfaction with social role
How much did pain interfere with your day-to-day activities? Not at all, A little bit, Somewhat, Quite a bit, Very much	Pain interference
How much did pain interfere with work around the home? Not at all, A little bit, Somewhat, Quite a bit, Very much	Pain interference
How much did pain interfere with ability to participate in social activities? Not at all, A little bit, Somewhat, Quite a bit, Very much	Pain interference
How much did pain interfere with your household chores? Not at all, A little bit, Somewhat, Quite a bit, Very much	Pain interference
How would you rate your IBD activity? Remission, Minimal symptoms, Mildly active, Moderately active, Severely active	N/A

Supplementary Table 2. A comparison of the Patient Reported Outcome Based Evaluation at baseline survey and follow-up (5-12 months) survey among patients with inflammatory bowel disease stratified by disease type and steroid use

	PROBE Initial	PROBE Follow up	p-value ^b
Patients with Crohn's disease			
Patients who never used steroids (n=2487)	23.4	23.1	<0.001
Patients who used steroids at baseline and who discontinued steroids prior to follow-up (n=206)	20.1	19.6	<0.001
Patients who did not use steroids at baseline and who initiated steroids prior to follow-up (n=154)	20.9	19.9	<0.001
Patients who used steroids at baseline and at follow-up (n=239)	20.2	21.0	<0.001
Patients with ulcerative colitis			
Patients who never used steroids (n=1453)	24.1	23.4	<0.001
Patients who used steroids at baseline and who discontinued steroids prior to follow-up (n=95)	20.4	22.3	0.005
Patients who did not use steroids at baseline and who initiated steroids prior to follow-up (n=72)	23.2	20.7	0.255
Patients who used steroids at baseline and at follow-up (n=94)	21.7	21.5	0.002

^a Disease activity defined as clinical remission or flare, where clinical remission was defined as a score of ≤ 2 on the Simple Clinical Colitis Activity Index for ulcerative colitis or a score of < 150 on the Short Crohn's Disease Activity Index for Crohn's disease

^b p-value obtained by Wilcoxon Rank Sum testing

Supplementary Figures 1a and 1b. Scatter plots depicting the relationship between the Short Crohn's Disease Activity Index (1a) and Simple Clinical Colitis Activity Index (1b) and the Patient Reported Outcome Based Evaluation

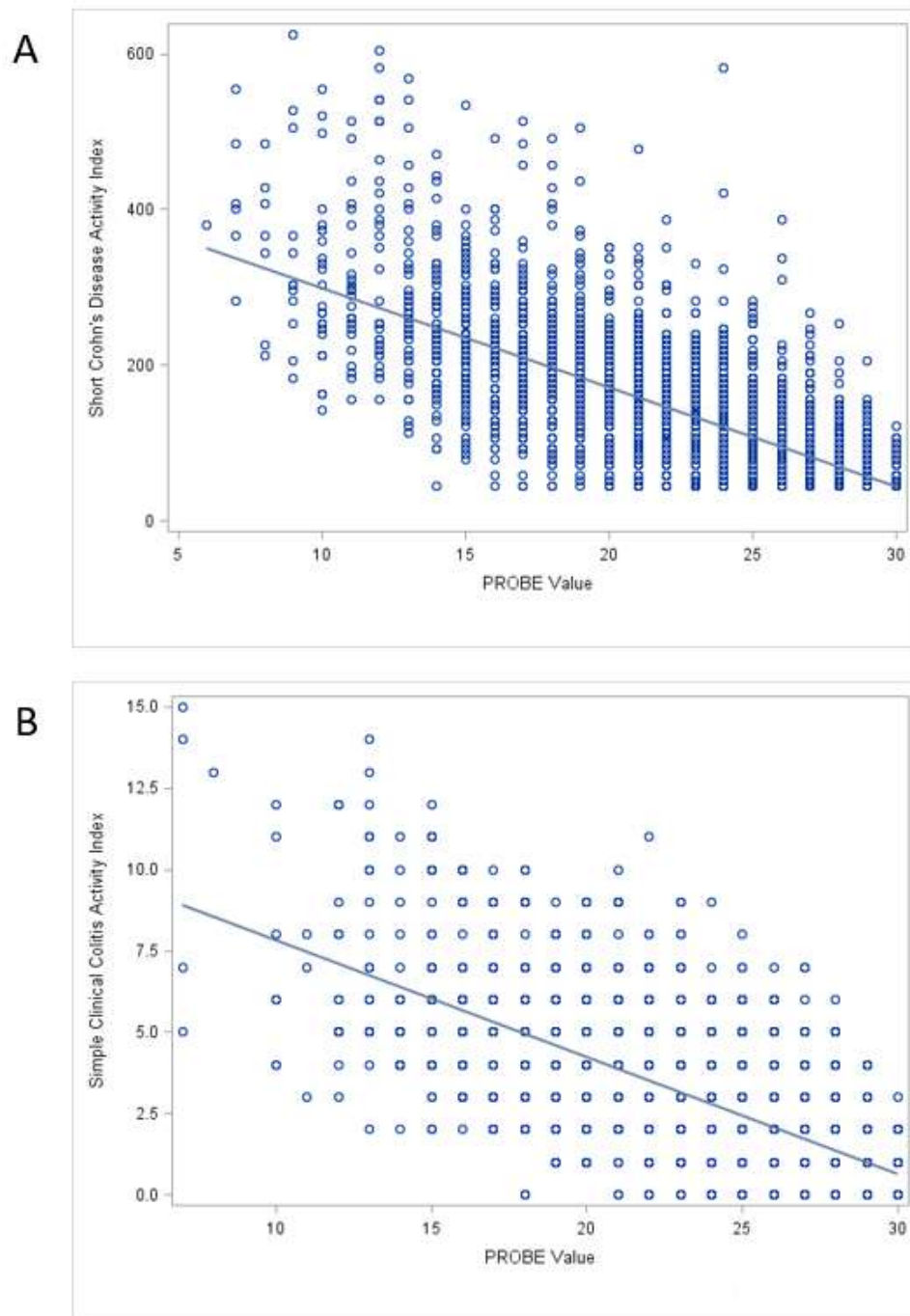
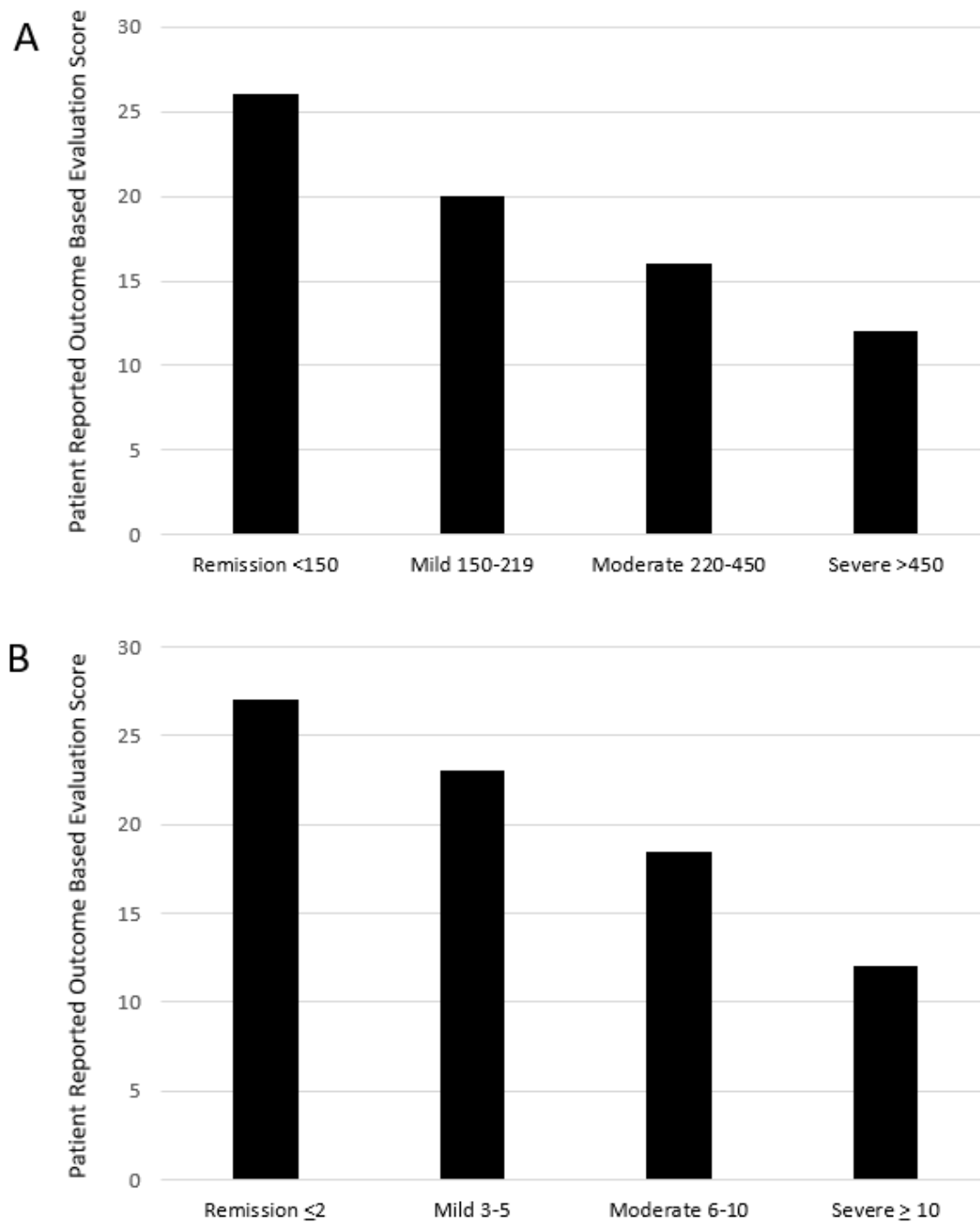


Figure Legend: Pearson correlation for Short Crohn's Disease Activity Index and Patient Reported Outcome Based Evaluation = -0.77. Pearson correlation for the Simple Clinical Colitis Activity Index and the Patient Reported Outcome Based Evaluation = -0.68.

Supplementary Figures 2a and 2b. Comparison of median scores on the Short Crohn's Disease Activity Index (1a) and Simple Clinical Colitis Activity Index (1b) and the Patient Reported Outcome Based Evaluation, when severity of flare is stratified



Figure

Legend: (A) $p < 0.001$ for comparison of PROBE scores across categories of disease flare, as defined by Short Crohn's Disease Activity Index (<150 remission, 150-219 mild flare, 220-450 moderate flare, >450 severe flare)¹⁷; (B) $p < 0.001$ for comparison of PROBE scores across categories of disease flare, as defined by Simple Clinical Colitis Activity Index (≤ 2 remission, 3-5 mild, 6-10 moderate, ≥ 10 severe)¹⁸